Original Contribution

Attitudes of Patients With Cancer About Personalized Medicine and Somatic Genetic Testing

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Abstract

Purpose: Dramatic advances in genomic technology stand to revolutionize cancer care; however, little is known about patients' understanding and acceptance of personalized medicine and widespread genetic testing (GT).

Patients and Methods: We conducted a formative, semi-structured interview study with a random sample of patients with lung, colorectal, and breast cancers to assess awareness of personalized medicine and GT and attitudes about somatic GT. Willingness to undergo GT was elicited through hypothetic scenarios.

Results: Sixty-nine patients participated; 71% were women; 42% were black; median age was 59 years; and 42% had an education level ≥ college. We found that a majority of patients either were not aware of the term "personalized medicine" or defined it in unexpected ways. Although many patients identified relevant benefits of somatic testing (eg, informs treatment), many patients also expressed significant concerns (ie, psychological harm and discrimination). A majority of patients expressed a willingness to undergo somatic (predictive, 96%, prognostic, 93%) and germline (cancer risk without incidental information, 87%; cancer risk with incidental information, 81%; pharmacogenetic, 91%) testing; however, far fewer patients expressed a willingness to undergo full genome sequencing (62%). Reluctance was attributed to concerns over incidental findings, information overload, and the lack of a clear benefit.

Conclusion: Many patients relayed misunderstandings about somatic testing and a reluctance to undergo full sequencing; oncologists must carefully consider how they present testing to patients so that concerns over discrimination and psychological harm do not hinder test uptake. More work is needed to identify effective ways to communicate complex genomic concepts to patients and research participants.

Introduction

The current revolution in genomic medicine has led to unprecedented advances in oncology. A refined understanding of the molecular drivers of carcinogenesis has allowed us to stratify patients into groups that differ in baseline cancer risk, risk of recurrence, and likelihood of response to treatment. The ability to stratify patients into subpopulations that differ in their susceptibility to disease or their response to treatment lies at the heart of personalized medicine.[1]

The personalization of cancer care has evolved over many decades. Early examples of personalized care include the use of all-*trans*-retinoic acid in acute promyelocytic leukemia[2] and prophylactic surgery in patients who harbor mutations in cancer susceptibility genes.[3,4] More recently, we have seen an explosion in genomically targeted drugs such as imatinib and erlotinib.[5,6]

Despite the availability of effective risk-reduction strategies for patients who carry germline cancer susceptibility mutations, we know that genetic testing is underutilized; approximately half of at-risk individuals are actually tested.[7-9] Although many factors influence testing, studies have shown that patients' attitudes about genetic testing play a critical role in test interest and utilization.[10-15] Whereas much is known about patients' attitudes about cancer susceptibility testing, less is known about patient attitudes about personalized medicine, somatic testing, noncancer risk germline testing, and full genome sequencing. Studies on somatic risk recurrence testing in breast cancer have demonstrated that patients' awareness of testing is low before diagnosis,[16] that a majority of women are willing to be tested, and that some women have concerns about testing.[17]

To realize the enormous potential of cancer genomics, we need to understand patient attitudes about a spectrum of genomic technologies. With this goal in mind, we designed a formative, qualitative interview study as an initial phase in our efforts to explore patient attitudes about and willingness to undergo genomic testing and to identify the domains of interest for future studies. This work represents an early, but critical, step in advancing our understanding of the factors that might promote or hinder patient acceptance of these life-saving technologies.

Patients and Methods

Study Population

Using random selection, we recruited patients with colorectal, breast, and lung cancers, stratified by race (white and black) and tumor type, at the Dana-Farber Cancer Institute (DFCI) between July 2010 and March 2011. Eligibility criteria included: age > 18 years; English speaking; ≥ two DFCI visits between January 1, 2008, and March 1, 2011; expressed willingness to be recontacted; and not enrolled in hospice. The study was approved by the institutional review board at DFCI.

Interview Guide

We developed a semi-structured interview guide that contained open-ended questions followed by prompts and closed-ended questions aimed at eliciting a response of "yes," "no," or "don't know." We first elicited awareness of and attitudes about personalized medicine and genetic testing in general. We then provided participants with definitions of somatic and germline genetic testing (drawn from patient-directed literature on the American Cancer Society[18] and American Society of Clinical Oncology[19] Web sites) to ensure a baseline level of knowledge about test types (Appendix Table A1, online only). We asked participants about their attitudes about somatic testing, followed by questions about the pros and cons of somatic testing framed in ways that were appropriate to the participant's personal experience with testing (eg, "What are some of the reasons that you got (*v* a cancer patient might want to get) a genetic test for acquired mutations?"). To contextualize participants' attitudes about somatic testing, we asked similar questions about germline testing. We also asked patients to identify potential barriers to genetic testing.

We elicited willingness to undergo genetic testing through the use of hypothetic scenarios. We asked participants to "think back to the last time that you were making a decision related to your cancer treatment. If your doctor had told you that you could have a test for each of the following situations, would you have wanted to have it done?" We then provided scenarios about somatic genetic testing that would help to inform a cancer treatment choice (somatic predictive) and that would help to determine the level of tumor aggressiveness (somatic prognostic); about germline testing that would reveal information related to the likelihood of cancer development (germline cancer susceptibility), the adverse effect and benefit profiles of medications or cancer treatments (germline pharmacogenetic), and medical conditions unrelated to cancer (eg, diabetes, germline incidental); and about their willingness to have all of the genes in their body tested (full genome sequencing).

The interview guide was reviewed by experts in cancer genetics, outcomes research, qualitative methods, genetic counselors, and clinical oncologists. On the basis of the feedback, the guide was refined, pilot tested with three patients, and finalized. The interview was written at a seventh-grade reading level and took approximately 20 to 40 minutes to complete.

Study Procedures

Study staff screened patients for eligibility. We gave each patient's oncologist the opportunity to opt the patient out of the study before patient contact. Patients who met eligibility criteria and whose physicians did not preclude contact were invited to participate. Contact procedures included a prenotification letter/opt-out card followed by a telephone call (telephone contact was attempted up to 15 times).[20] Willing patients were scheduled for a telephone interview. Interviews were conducted by the DFCI Survey and Data Management Core (Survey Core), whose research staff includes qualitative methodologists. One pilot interview was conducted by S.W.G. Interviews were transcribed for accurate data capture. A $50 incentive was offered to participants. Two team members independently coded transcripts to identify themes in predetermined categories of interest (eg, definition of personalized medicine). A third team member reviewed coded data to confirm similarities in themes. Transcripts were analyzed according to a two-stage, standard qualitative analytic process by the DFCI Survey Core using NVivo 8 (QSR, Doncaster, Victoria, Australia). We conducted a limited medical record review to obtain information on clinical variables, including prior genetic testing. Descriptive statistics and bivariate associations (Pearson's χ^2 tests) were generated in STATA 11 (STATA, College Station, TX).

Results

Sample Characteristics

Of 111 eligible patients, 69 completed interviews for a response rate of 62%. The sociodemographic characteristics of our sample are listed in Table 1.

Awareness and Definitions of Personalized Medicine and Cancer Genetic Tests

Forty-eight percent of participants had heard the phrase personalized medicine, 46% had not, and 6% were unsure (Appendix Table A2, online only). Participants who had undergone germline genetic testing before the interview (as identified by medical record review) were less aware of the phrase personalized medicine than those who had not undergone germline testing (18% *v* 55%). Of those who had heard the phrase personalized medicine, patients gave a range of definitions, including treatments that are tailored to individual patients and medical care that involves genetic testing. Nineteen percent of aware patients provided definitions that had little to do with treatment individualization or genomic medicine, including defining personalized medicine as a patient's ability to participate in medical decisions, as care that patients purchase over the counter, and being in constant contact with one's physician.

Seventy-four percent of participants had heard of cancer genetic tests (3%, unsure; 23%, no). Sixty percent of aware participants defined them as tests to determine cancer susceptibility or familial risk. Fewer participants defined testing as an evaluation of tumor DNA or proteins (12%). Three percent of aware participants were not able to provide a definition.

Attitudes About Somatic Genetic Testing

Ninety-six percent of participants reported that our explanations of somatic and germline genetic testing "made sense" to them. Of the three people who did not endorse this statement, two participants said that they understood the definitions "a little bit" or "kind of," and one participant reported that "it takes a little while to absorb [information] due to [his] age."

When we asked participants about the benefits (ie, "good things") of somatic testing, patients reported many advantages that are relevant; 50% of participants stated that somatic testing could be used to select treatments or clinical trials. Fewer par-

Table 1. Patient Demographic and Clinical Characteristics (n = 69)

Characteristic		%
Female sex		
Lung		54
Colorectal		58
Breast		100
Age, years		
Median	59	
Range	32-86	
Race		
White		58
Black		42
Highest level of education		
≤ High school		30
Some college		28
≥ College graduate		42
Employment status		
Full time		38
Retired		25
Other		37
Marital status		
Married/living with partner		64
Single		36
Cancer type		
Lung		38
Colorectal		27
Breast		35
Stage		
0		1
I		13
II		28
III		36
IV		22
Disease status		
Active disease		55
NED		45
Treatment(s)		
Surgery		77
Radiation		55
Chemotherapy		80
Targeted therapy		39
Hormone therapy		29
Prior genetic testing		
Germline		16
Somatic		70

Abbreviation: NED, no evidence of disease.

ticipants said that somatic testing could be used to learn about the causes of cancer (21%), to help physicians and scientists treat cancer (10%), and to learn prognostic information (3%; Table 2). However, participants also attributed some advantages to somatic testing that are normally associated with germline testing; participants reported cancer prevention or motivations for behavior change (22%) and earlier diagnosis and treatment (13%) as possible advantages.

When asked about the disadvantages (ie, "not-so-good things") of somatic testing, 29% of participants noted no disadvantages, whereas 71% reported disadvantages (Table 2). Many participants thought that somatic testing would disclose unwanted information or felt that it could counteract denial (43%). Additional downsides included concerns over psychological harm (32%), cost (9%), and privacy (3%). Concerns over psychological harm were higher among blacks as compared with whites (48% *v* 20%) and among patients with colorectal as compared with breast and lung cancers (63% *v* 29% and 12%, respectively), and they were lower among patients who had undergone somatic testing as compared with those who had not (21% *v* 57%). Six percent of patients reported concerns over health insurance, life insurance, and/or employment discrimination in open-ended questioning, and that number increased to 44% on probing. Participants described a number of potential barriers to obtaining genetic testing, including concerns over insurance reimbursement and cost (Appendix Table A3, online only).

Willingness to Undergo Genetic Testing

We used hypothetical scenarios to ask participants about their willingness to undergo testing (Table 3). There was high reported willingness to undergo somatic predictive (96%) and prognostic (93%) testing as well as germline pharmacogenomic (91%) and cancer susceptibility (87%) testing. Participants reported somewhat lower willingness to undergo germline testing that reveals incidental information (81%), largely because they did not want to worry about conditions that they might not get. Participants were much less willing to undergo full genome sequencing (62%, yes; 30%, maybe). Willing patients cited reasons such as wanting to know what conditions they could pass onto their children, hoping that full sequencing could save or prolong their lives, and satisfying their curiosity. Themes related to reluctance to have full sequencing included information overload; too much information about noncancer disease; unclear benefit; and concerns over privacy, test accuracy, and testing procedures. There were no differences in willingness to test by patient subgroup.

Discussion

We are witnessing a paradigm shift in oncology; as our understanding of the molecular drivers of cancer improves, we will increasingly develop genomically guided therapies that will help patients live longer and better lives. Whereas scientists and clinicians anxiously await the era of personalized medicine, little work to date has examined views of patients with cancer about personalized medicine or their attitudes about a wide range of genomic tests. The results of this study provide unique insight into these issues and address some of the knowledge gaps in this area.

Although the benefits of personalized medicine are widely touted, our study suggests that personalized medicine may not

Table 2. Attitudes About Somatic Genetic Testing

Attitude	Example
Benefits	
Select treatment	"I mean, in my case, they targeted that specific gene, and . . . and not, no other part of my body, which I thought was really amazing because I could be treated and not feel sick."
Clinical trial eligibility	"It was more or less to find out what study to get in . . . what study I'd be able to get into."
Identify cause of cancer	"Just to figure out how they got it in the first place, and how they can prevent getting it at any other later point in their life. And, with respect to, uh . . . prevention, as it relates to family members and friends."
Gain prognostic information	"Just to be more knowledgeable about the degree and, uh . . . type of cancer—if it's an aggressive type."
Prevention/early diagnosis	"Catch things early, and . . . take preventative measures."
Promote behavior change	"I don't know that those [tests for acquired mutations] would inform their family members of the same risk, if it's not a genetic hand me down . . . But it certainly could change their behavior if they're, uh . . . yeah, it would be a strong incentive to change behavior."
Promote research	"If it can help cure, or get a cure [chuckles] if there's such a word . . . they're still looking for a cure, so and you know, if mine can help the scientists or whatever to reach that goal? Well, all right!"
Concerns	
None	"Jesus, I can't think of anything. I mean, I can't think of . . . why anybody wouldn't want to have the test done. The only thing I wished, I had had it done sooner."
Psychological harm	"Fear. You know? Paralyzing your life and going forward, and not know when it's going to creep up, if it's going to creep up, and where."
Do not want to know	"But, just to do the testing to find out that I may have concern somewhere in my body, or I may down the line have cancer somewhere else in my body and then to worry about whether or not it's going to pop up somewhere? No. I don't think I'd want to do that."
	"I would say fear. Uh, fear would be at the top of the list. Some people would rather not know [about testing for acquired mutations]."
	"[The patient] is . . . not being honest with themself about how they're living their life, and they don't want to know . . . Or, you know, confront their demon, so to speak."
Cost	"If the insurance companies say, "This is going to cost $5,000 and we're not going to cover it,' then people would say . . . "I can't afford to do that.'"
Discrimination	"I am red flagged, the rest of my life, through my . . . through my insurance carrier. I've been told that . . . And for me to, um, get on a different insurance plan, I think, would be really difficult for me to . . . I'm high risk."

Table 3. Patient Willingness to Undergo Genetic Testing

	Yes		Maybe	
Type of Test	**No.**	**%**	**No.**	**%**
Somatic				
Predictive	66	96	2	3
Prognostic	64	93	2	3
Germline				
Cancer susceptibility	60	87	3	4
Pharmacogenomic	63	91	3	4
Incidental	56	81	3	4
Full sequencing	43	62	21	30

Themes Related to Reluctance to Test	Example
Concerns over incidental information	"I don't think if I had three or four different things I had to deal with, along with the cancer, that that would . . . you know, necessarily help my mental state!"
Concern over information overload	"Well, it's like opening a Pandora's box, isn't it [chuckles], um . . . I don't know. I honestly . . . I can't give you a yes or a no answer on that . . . Like the cancer was something concrete, and I know, my father had Marfan's syndrome, so I knew those two things were concrete that we had to watch for. But the other stuff? I, I don't know. I guess part of me would want to know, but another part would just say, "You know what? Just live your life the best you can, and enjoy it and see what happens.""
Not test unless there is a clear benefit	"I just want them to deal with what they have to deal with right now, and get me better . . . I get poked and prodded so much right now that, you know, unless it had something to do with getting me better with what I'm dealing with now, no. That, I, I don't really think so."
	"[I would] only [have all of the genes in my body tested] if I had an end result outcome objective in mind . . . I wouldn't do testing just for testing's sake."
	"I can't imagine doing that unless there was a benefit, because I, I think that, you know, we're spending too much on healthcare now, and that just seems like it would tremendously raise the cost."

be a highly relevant term for some patients. In addition to lower-than-expected reported awareness of personalized medicine, we were surprised to find that a sizeable minority of patients conceptualized personalized medicine as care that was patient friendly or independent of a physician. This conceptualization of personalized medicine is consistent with the movement toward patient-centered care.[21,22]

Our study also explored patients' attitudes about somatic genetic testing. Many participants reported benefits and concerns related to somatic testing that are reasonable given the implications of tumor profiling. Participants reported that somatic testing may help to identify treatments or clinical trials, and both of these concepts are consistent with contemporary practice (eg, *KRAS* testing in colon cancer and cetuximab therapy[23]). Some participants also correctly identified the fact that somatic testing can have prognostic implications (eg, *IDH1* testing in giloblastoma[24]). Participants also expressed relevant concerns related to somatic testing, including cost, accuracy, and the potential need for rebiopsy.

In contrast, however, when asked about somatic testing, participants also reported a number of benefits and concerns that are instead associated with germline testing. Similar to what has been described in the germline cancer genetics literature,[11,13-15,25,26] patients in our study reported that somatic testing might be beneficial in defining familial risk and identifying cancer prevention options. Previous work has also shown that people have concerns about psychological harm, test-related distress, and discrimination in the context of cancer susceptibility testing.[11,13-15,26,27] Similarly, our patients expressed concerns over life insurance, health insurance, and employment discrimination and test-related distress in the setting of somatic testing. This finding is notable, because almost all of our participants reported that our definitions of somatic and germline testing "made sense" to them. Participants may have misattributed some of the benefits and concerns related to germline testing to somatic testing, because there has been a longer public discourse about germline testing or because they used inductive reasoning to generalize their attitudes about germline testing to genetic testing more generally.[28] It is also possible that the term genetic testing itself raises thoughts about familial risk, psychological harm, and discrimination because of the fact that these issues arise in genetic testing for other diseases.[29,30]

An alternative explanation for patients' misattributions is that patients did not understand our definitions but stated that they did because of social desirability (a participant's motivation to represent himself/herself in a positive way during an interview).[31] If patients' misattributions stemmed from a misunderstanding of genomic concepts, we must carefully consider the reasons why they did not understand. First, patients may have had a harder time understanding concepts relayed over the telephone than if they had been written down. Second, genomic concepts are complicated, and it is possible that some patients may need much more, or possibly less, detail to understand test distinctions. There is also the possibility that this type of information triggers anxiety, which may impede comprehension.

Finally, although some reported risks and benefits are unlikely to occur with somatic testing (eg, identifying familial risk), studies have shown that somatic risk recurrence testing may be associated with negative psychosocial outcomes. Up to 26% of women who had somatic risk recurrence testing for breast cancer reported test-related distress,[16] and 5% of women reported that testing had a negative impact on their families.[32]

The fact that some of our participants had significant misunderstandings about the benefits and downsides of somatic testing raises a fundamental issue related to test dissemination; as a field, we need to consider carefully the language that is used to convey genomic concepts to patients. If the term genetic testing automatically elicits concerns about discrimination and distress, and we believe that test-related discrimination and distress are unlikely to be a result of certain types of testing, then it might be important to use different terminology. A key area for future research will be to better elucidate how the language and presentation of genomic concepts affects patients' willingness to undergo testing. For example, are some genomic terms more accessible to patients than others? Are visual representations of genomic concepts necessary? Will oversimplification of concepts (eg, testing "your tumor's genes" *v* "your genes") improve patient understanding? Experimental studies that evaluate genomics-related language and that try to tease out the relative importance of other factors that influence patient decision making (eg, cost) are needed. Given the complexity of genomic concepts, it is also essential that investigators of future studies pretest genomics-related language for comprehension.

It is imperative that we learn how to communicate genomic concepts to a broad range of patients, because comprehension and concerns about testing have been shown to vary across different populations. In the setting of cancer risk recurrence testing, test-related concerns were higher in less educated patients.[17] Additionally, over 30% of patients did not understand "a large amount" of what they had been told.[16] Post-test knowledge was lower among nonwhites; older individuals; and those who had lower levels of income, education, and numeracy.[32,33] To fully understand how attitudes and willingness to test may vary across groups, it is essential that research in this area be conducted in more diverse populations. The ultimate goal of such research will be to identify the terms that should be used in clinical practice to ensure that providers effectively communicate the benefits and implications of different types of genetic tests to their patients.

In line with prior work,[17,34-41] our study suggests that most people are willing to undergo emerging genetic tests, but whether this will translate into actual behavior is unclear. Our study also provides evidence that some patients may be reluctant to undergo whole genome sequencing or tests without clear utility. As the cost of sequencing decreases, there is the expectation that full sequencing of germline and tumor DNA will rapidly enter clinical practice. At this critical juncture, it is essential that we strive to understand how patients view these technologies and work to identify patient-related barriers to test adoption.

Although this study provides rich, qualitative data related to patients' attitudes about personalized medicine and genomic testing, it is limited in a few ways. Patients in this study received care at an academic medical center, and therefore, the results are not generalizable. Second, although we generated genetic testing definitions from information obtained on patient-centered cancer Web sites, it is possible that different definitions might elicit different attitudes or intentions. Third, social desirability bias can complicate studies; we attempted to limit social desirability bias by normalizing responses and encouraging participants to ask questions. Finally, our study did not evaluate the influence of cost, insurance reimbursement, or health system structures on patients' willingness to undergo testing. More work in these areas is needed.

In summary, we found that personalized medicine was not a phrase that was particularly meaningful to many patients, that some patients reported downsides of somatic testing that are more commonly associated with germline testing, and that many patients reported a reluctance to undergo whole genome sequencing. Although many patients expressed a willingness to undergo genomic testing, they also described concerns and barriers that could hinder test uptake. Taken together, these findings shed some light on patients' perceptions of emerging genetic technologies. More work in this area is needed to provide clinicians and researchers with a refined understanding of how to effectively communicate complex genomic concepts to a broad range of patients; without this, we may fail to optimize the delivery of cutting-edge genetically guided cancer care.

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Appendix

Table A1. Definitions of Somatic and Germline Genetic Testing

Term	Definition
Introduction	Genes play an important role in the development of cancer. Changes in genes are called mutations. There are some genes that are important in making sure that our cells grow in a healthy way. Mutations can cause cells to grow out of control, which can lead to cancer. There are two basic kinds of genetic mutations.
Germline testing	One type of genetic change is an inherited mutation. • When a mutation is directly passed from a parent to a child, it is an inherited mutation. This means that the mutation is present in every cell of a person's body and is passed from generation to generation. Inherited mutations are responsible for 5% to 10% of cancer cases. One type of genetic test looks for inherited mutations. These tests are often done on blood or cheek cells. Genetic tests for inherited mutations are used to look for gene mutations that might put a person at risk of getting cancer. • Examples of tests for inherited mutations include *BRCA1* and *BRCA2* tests for breast cancer, and *APC* or *HNPCC* mutation tests for colon cancer. In lung cancer there are no commonly used tests for inherited mutations.
Somatic testing	Another type of genetic change is an acquired mutation. • Acquired mutations occur during a person's life and are not passed from parent to child. These mutations are caused by tobacco, UV radiation, viruses, age, and other factors. Acquired mutations are responsible for the majority of cancer cases. A second type of genetic tests looks for acquired mutations. These tests are often done on cancer cells. Genetic tests for acquired mutations can give information on a person's outlook (prognosis) or even on how much he or she might benefit from certain types of treatment. • Examples of tests for acquired mutations include *KRAS* and *BRAF* tests for colon cancer, and *EGFR* and *ALK* tests for lung cancer. In breast cancer OncotypeDX and *HER2* tests evaluate for genetic changes in breast tumors.

Abbreviation: UV, ultraviolet.

Table A2. Awareness of and Themes Related to Personalized Medicine

Aware of Personalized Medicine	No.	%
Yes	33	48
No	32	46
Don't know	4	6

Definition of Personalized Medicine	Example
Treatments tailored to individual	"Um . . . well, to me, I think it's . . . it's tailoring treatment to the particularities of an individual's illness."
Medical care that involves genes/genetics	"That somehow it's looking at your genes and developing the treatments, based on what your genes show."
Care that a patient feels he/she needs	"That would mean something that, uh, you felt that you needed, personally, and you wouldn't want it cut off. That's . . . that's what I get out of it."
Care/medication outside of what is provided from a physician	"Well, personalized medicine, meaning . . . I have got my own medicine? Or my own, like, you know, over the counter . . . not hospital medicine, you know, be that . . . over, what, the radio or TV, and you . . . you know, you buy them over the counter, or you send them, sent away for those medicines."
Active participation in medical decision making	"Personalized medicine to me means that the patient is involved in the treatment and they would discuss it with their provider and decide what options were best for them . . . the participation is what makes it personalized."
Being in constant contact with a physician	"Like, you're . . . If you're seeing one doctor all the time, and he knows your history, and you just keep in contact to make sure that you're healthy . . . That's what I would imagine it would be."

Table A3. Barriers to Genetic Testing

Barrier	Example
Insurance reimbursement	"Main reason would be insurance, if their insurance doesn't pay for it, the testing."
Cost	"I mean, I know the test that I had was incredibly expensive . . . I do think cost is a factor for a lot of people."
Fear/denial	"Well, I mean, there probably are people who go through life with blinders, you know. They don't want to know if there might be a problem, because then they're going to worry about it."
Access to testing/transportation	"It depends on what part of the country you're in. I don't think the average person would be getting all these tests, uh, if you live in the deep South, or some place like that."
Risks of procedure	"The only thing I could say was maybe that procedure is risky?"
Confidentiality	"I think the biggest . . . uh, the two biggest reasons for not getting tested are your, um, employer or your insurance agent finding out, which, I'm sure they could . . . I, I'm sure they could find out."
Provider reluctance	"I think sometimes they [health care professionals] make the decision not to offer certain things to certain people and certain cultures . . . based on what they think they know, or . . . may have experienced."